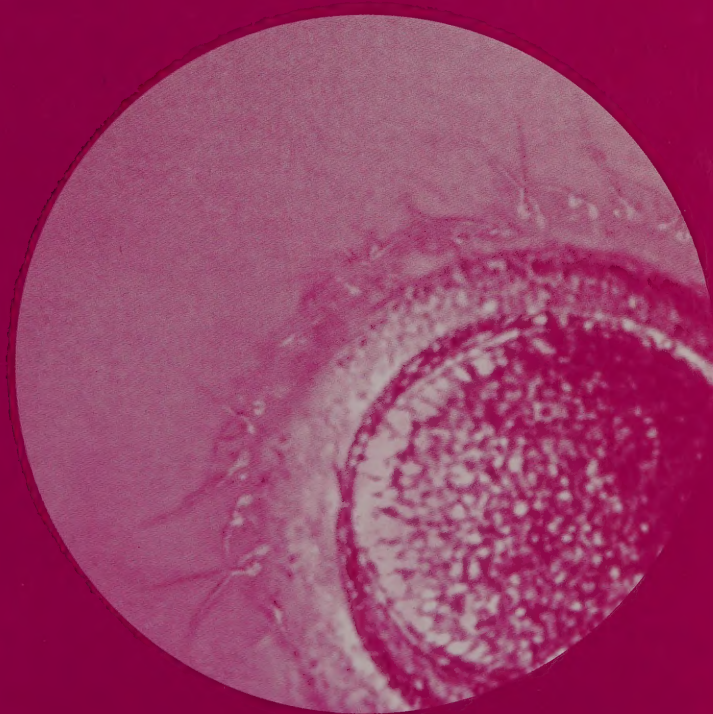


The Patients' Guide to Infertility and IVF



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The 'Patients' Guide to IVF Clinics' and 'The Patients' Guide to DI'

Infertility affects many people. Up to one in seven couples have problems conceiving and many seek medical advice and treatment.

Some patients will need only advice or reassurance. Others may need drug therapy or surgery. But some will need to be referred to a clinic which specialises in assisted conception techniques – including *in vitro* fertilisation (IVF), intra cytoplasmic sperm injection (ICSI), and donor insemination (DI). These treatments can be provided only by clinics licensed by the HFEA.

If you are interested in donor insemination (DI), then you should see the HFEA's booklet 'The Patients' Guide to DI'. If you are interested in donating eggs, you should see the HFEA leaflet 'Egg donation'.

Purpose of this booklet

The purpose of this booklet is to help people who are considering IVF or ICSI to understand the services offered by licensed clinics and to decide which would be the best clinic for them. We try to explain briefly what is involved in these treatments and look at some of the questions and issues that you may wish to think about.

PLEASE NOTE

We are writing this booklet as if for a couple. We appreciate that not all patients are in a relationship. The information contained in this booklet is relevant to all those seeking treatment.

For your assistance a glossary of commonly used terms can be found on pages 22-23.

Choosing a clinic

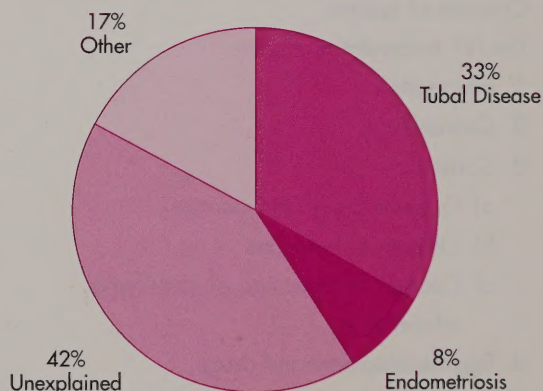
The separate 'Patients' Guide to IVF Clinics', HFEA booklet gives information about all licensed clinics, and is designed to help you decide which clinics to consider. As every patient has different circumstances, you should not look just at clinics' 'success rates'. You should take into account the many other aspects that may well be relevant to you, such as a clinic's location, multiple birth rates, restrictions on treatment and costs. A visit to the clinic can also be worthwhile. If you do

not have a copy of the 'The Patients' Guide to IVF Clinics' you should telephone the HFEA for a free copy (020 7377 5077).

What is 'infertility'?

The male and female reproductive systems are intricate, and unfortunately many things can go wrong within a lifetime. Although the word 'infertility' is commonly used, to be 'infertile' is actually rare and means a total absence of reproductive function. Most people seeking treatment have a varying degree of what is known as 'sub-fertility'. One or more parts of their reproductive systems are impaired in some way, and they may well need some medical help to conceive. In this booklet we use the word 'infertility' to include 'subfertility'. Infertility equally affects both men and women. For men it is most commonly due to poor sperm quality or quantity. For women it can be due to a number of factors (see FIG.1 below).

FIG.1 causes of female infertility



Tests and investigations

The first thing to determine, if possible, is the cause of your infertility. If this is investigated thoroughly you are more likely to receive the most suitable treatment. Usually the cause of infertility will be investigated following a referral from your GP to an infertility clinic.

If the cause of your infertility has not been investigated previously, you may wish to ask what tests a clinic proposes to carry out. These tests may include an analysis of the man's semen and the condition of the

woman's womb and fallopian tubes. Some clinics have a routine set of investigations and you should ask what these include.

If tests have been done during previous investigations, you should ask whether it is necessary to repeat them. If you have already undergone investigations, you should enquire whether additional tests will be required. Even after tests infertility can remain unexplained in up to 30% of couples, but that does not mean that your infertility cannot be successfully overcome.

Different causes of infertility may require different treatments. It is important for you to be confident that the treatment you are being offered by a clinic is appropriate for your type of infertility. Not all clinics offer all forms of treatment. While some specialise in a particular treatment, others provide a range of treatments and may be able to offer the option of a different approach if one type of treatment is not successful.

You should expect the doctor at the clinic to explain why a particular fertility treatment is being recommended.

Because there are many possible causes of infertility or sub-fertility in both men and women there are also many possible treatments, including those described below. The first four of these treatments are not necessarily regulated by the HFEA and may therefore be offered, for example, by licensed clinics, local hospitals or GP's.

1. Ovulation induction (hormone treatment)

At least 20% of women attending a fertility clinic will have an ovulation problem. Hormone therapy can be used to stimulate ovulation if a woman is not producing eggs regularly.

2. Artificial insemination (AI) using the partner's sperm and intra-uterine insemination (IUI)

AI may be used to overcome potential problems such as thickening of female mucus, premature ejaculation, impotence or anatomical abnormalities. AI enables the sperm to be inserted directly into the cervix via the vagina. Intra-Uterine Insemination (IUI) is essentially the same as AI but usually combines ovarian stimulation for the woman and preparation of the semen.

3. Tubal surgery to improve blocked or damaged fallopian tubes

Approximately a third of female infertility problems are due to damaged fallopian tubes. Damage may have been the result of previous infection. Depending on the severity of tubal damage surgery may be appropriate

and, if successful, fertility may be permanently restored. For some types of tubal damage IVF may be considered. Discuss this with your doctor.

4. Gamete intra fallopian transfer (GIFT)

This technique can be used in unexplained female infertility and, rarely, with male sub-fertility. The eggs are collected from the woman (see IVF, pages 6-9), mixed with sperm and then the eggs and sperm are transferred to the fallopian tube before fertilisation takes place. This means that the sperm do not have to travel the length of the reproductive canal before encountering an egg. The HFEA licenses this procedure if donated sperm or eggs are used.

5. In vitro fertilisation (IVF)

IVF is often used in cases of tubal damage, endometriosis, low sperm count, mucus hostility and 'unexplained infertility'. Following a period of hormone stimulation, a number of eggs are collected from the woman and mixed with the man's sperm. Fertilisation occurs in the culture dish. Up to three of any resultant embryos can be placed in the womb. Where appropriate, IVF can also be used with donated eggs, sperm or embryos (see page 8).

6. Intra cytoplasmic sperm injection (ICSI)

ICSI may be appropriate when the male partner has very few sperm. It involves IVF, with a single sperm being injected directly into each egg. As with IVF a maximum of three fertilised eggs can be transferred back into the womb (see page 9).

7. Donor insemination (DI)

DI involves the use of sperm from an anonymous donor. It can be used if the husband or partner has no sperm, few or poor sperm, or risks passing on an inherited disease. Some clinics may offer DI to single women or lesbian couples. See the separate HFEA booklet, 'The Patients' Guide to DI', for more information.

8. Surgical sperm recovery

Sometimes sperm are produced in the man's testes but are unable to enter the seminal fluid because the vas deferens (the tube which carries sperm outwards from

the testes) may be obstructed or absent. If this is the case, the sperm may be extracted directly from the testis (TESA) or the epididymis (PESA or MESA). Sperm extracted in this way would normally be injected into the egg using ICSI (see page 9).

IN VITRO FERTILISATION (IVF)

'In vitro fertilisation' means fertilisation outside the body. It is a method which has helped many women to have babies since 1978 when it was first used successfully. IVF treatment is now offered at over 70 UK clinics. All are licensed and monitored by the HFEA.

Briefly, IVF involves the collection of eggs and sperm which are mixed outside the woman's body in a culture dish. Any eggs which fertilise and become embryos are left to grow for up to two days and then up to three embryos are transferred into the woman's womb. If the treatment is successful, one or more embryos will implant in the lining of the womb and for each a fetus and placenta will develop. The woman will then be pregnant, as if she had conceived naturally.

The law requires that everyone has to undergo an assessment at the fertility clinic before treatment is offered (see 'welfare of the child', page 17 question 3).

When is IVF advised?

IVF treatment is just one of the treatments for fertility problems. It may be appropriate if:

- the woman has blocked fallopian tubes, endometriosis, or cervical mucus problems;
- the infertility is largely due to male factors;
- the infertility is unexplained.

IVF using donated eggs may be offered to women suffering premature menopause, those whose eggs will not fertilise, those whose ovaries have been removed or older women.

Chances of success

The average success rate for IVF is about 17% per treatment cycle, and slightly less (about 12%) for frozen embryo transfer. Generally, the chances of success decrease with the woman's age. However, your chances will very much depend on your own individual circumstances – see 'FIG. 3, page 11' for more detail.

The IVF treatment procedure

There are several things you should be aware of before starting treatment.

1. Information

During the course of treatment a clinic has a legal obligation to collect information, including personal details such as your name(s), date(s) of birth and some medical details. This information is passed to the HFEA which holds it in its computer register. The HFEA keeps a register because it has a legal obligation to tell adults who may ask in the future whether they were born as a result of IVF or DI (licensed treatments).

2. Counselling

There are many considerations to be taken into account when deciding on fertility treatment. To help you, clinics are required by law to offer you an opportunity to talk through any issues and concerns either of you may have with someone not immediately involved with your treatment (see page 13).

3. Consent

Written consent must be given before treatment begins. You should only give your consent once you are satisfied that you understand what you are agreeing to. Because the issues can be particularly personal and far-reaching, the law requires that you complete special HFEA consent forms that address various questions. You will be asked to make important choices. You should feel that you have had the opportunity to consider the implications of what it is you are being asked to agree to. The different types of consent are explained in the following paragraphs.

a) Consent to use and storage

Both you and your partner must give your individual consent to the use and storage of your own gametes or embryos created. Either of you will be able to vary or withdraw this consent until such time as the embryos that may have been created have been implanted or used in research (see page 14).

b) Consent to treatment

As in many medical situations (e.g. anaesthetics or surgery), you will be asked by the clinic to give written consent to your fertility treatment, such as egg collection and to the transfer of a specified number of

embryos into the womb. If donated sperm or donated eggs are used, you will be asked to give consent to treatment using these and to embryo transfer.

c) Consent to disclosure of identifying information

Finally the law requires that, before a clinic can tell your GP or someone else who may need to know about your IVF treatment, your written consent to disclose identifying information must be obtained. You may wish to consider what information you may wish to allow to be disclosed and to whom.

4. Egg development and drugs

Normally, every month a woman's ovaries begin to develop several eggs but only one of these becomes fully mature. This egg is released into the fallopian tube where it may be fertilised following intercourse. IVF involves a small operation to collect eggs, and clinics prefer to try to collect more than one egg at a time. To do this they give the woman hormones ('stimulated cycle'). These generally cause the ovaries to mature several eggs in one monthly cycle which can then be collected. Some clinics prefer not to use these drugs, but collect the one, or occasionally two, eggs that may be produced naturally in a monthly cycle ('unstimulated cycle').

If drugs containing hormones are given, they will usually be of three types:

- a nasal spray or an injection given every day throughout the 28 day cycle. These drugs suppress the hormones produced by a woman in a normal menstrual cycle and enable greater control over when the eggs are produced (also known as down regulation and desensitisation);
- an injection or tablet once a day for approximately the first five days of the cycle. The injections or tablets are hormones which stimulate the ovaries. These are given so that more than one egg develops, and are known as superovulatory drugs;
- when the ultrasound scanning and/or hormone measurements show that an adequate number of eggs are maturing, a final hormone injection is given which completes the maturing process. This injection must be carefully timed 34-38 hours before egg collection so that the eggs will be mature, but will not have left the ovary.

The injections may be given at the clinic or sometimes arrangements may be made for your GP, practice nurse or local hospital to give them. Often the last injection is late at night and this may cause some inconvenience. Several of the injections can be self-administered after training.

5. Egg collection

When the eggs have matured, one of two techniques are used for their collection.

a) Ultrasound guided egg collection

The most common technique, this may be done under a mild sedative or general anaesthetic. A fine hollow needle is passed under ultrasound guidance via the vagina and each egg is removed in turn. Occasionally it may be necessary to pass a needle under ultrasound guidance through the abdominal wall.

b) Laparoscopy

A small cut is made just below the navel for a laparoscope (an instrument for looking into the abdomen) to be inserted and a fine, hollow needle is inserted separately to remove the eggs. A general anaesthetic will normally be necessary. Laparoscopy carries the minor risks and side-effects of any procedure requiring a general anaesthetic and the insertion of gas and instruments into the abdomen.

6. Sperm collection

A couple of hours before the egg collection procedure is performed the male partner will be asked to produce a sample of sperm. The sample will be prepared to be combined with the eggs. If donor sperm is to be used, the sample will be taken from frozen storage and will be prepared for fertilisation.

7. Fertilisation

The eggs are also prepared and placed in an incubator. After about 3-6 hours, depending upon their maturity, the eggs and sperm will be placed together in a specially prepared culture medium. This medium is prepared in a carefully labelled dish that is kept in an incubator and inspected the following day to see whether the sperm have fertilised the eggs. If they have, the resulting embryos will be left to grow for a day or two longer.

8. Embryo transfer

The embryologist will check that the embryos are developing satisfactorily and up to a maximum of three may be transferred into the womb by using a fine plastic tube (a catheter). A clinic can transfer up to a maximum of three embryos. Furthermore, in order to reduce the chance of a multiple pregnancy (see page 12) particularly triplets, the clinic may advise that only one or two embryos are replaced. This will not necessarily reduce the risk. The clinic will advise whether any remaining embryos are suitable for freezing for treatment at a later date. Not all clinics are able to offer freezing facilities.

What happens next?

Usually the doctor will prescribe further hormone injections or vaginal pessaries to assist implantation. This will depend upon the levels of hormones already in the blood and the type of drugs that have already been given. Advice will also be given as to lifestyle pending a pregnancy test that will generally be performed two weeks after embryo transfer.

The extent to which clinics will remain involved after this will vary. Some clinics may carry out the pregnancy test and some of the antenatal care; others transfer patients to the care of their own GP or consultant straight away. **Whether successful or not, the clinic needs to know the outcome of the treatment.** It will be able to offer advice and support, if necessary.

Risks of IVF

Some women experience mild unpleasant symptoms as a reaction to the drugs, but these are normally short-lived and are no cause for concern. They may include hot flushes, feelings of depression and irritability, headaches and restlessness at night.

Despite careful monitoring, a small number of women may develop ovarian hyperstimulation syndrome (OHSS). The majority of these women have a mild or moderate form of over-response to the drugs, and complain of pain and mild abdominal swelling. In some cases cysts may appear on the ovaries and fluid may collect in the abdominal cavity causing discomfort. The condition should be monitored by a fertility specialist,

and in some cases the cycle may have to be abandoned.

In about 1-2% of cases the ovarian hyperstimulation is severe and the ovaries are very swollen. The woman will feel ill, with nausea and vomiting, abdominal pain and swelling and shortness of breath. She may also feel weak and faint and notice a reduction in urine output. These complications require urgent hospital admission to restore the fluid balance and monitor progress.

Patients should:

- ask for information about how the clinic tries to avoid OHSS;
- be made aware of the symptoms to look out for.

If you are at all worried during treatment, you should always contact the clinic. Their phone numbers (including an emergency phone number) should be easily found in their information leaflets.

Satellite IVF

Because some areas of the UK do not have many IVF clinics, a number of clinics offer services known as "satellite IVF". In satellite IVF the woman begins the superovulatory drugs and is monitored at a clinic or hospital closer to her home than the licensed IVF clinic. Some clinics are able to offer a choice for the egg collection to take place at her home clinic or the IVF clinic. You could also be offered transport IVF where eggs removed at the home clinic are transported to a licensed IVF clinic. Embryo transfer will always take place at the licensed clinic. If there are no IVF units close to you, then you may wish to ask the Obstetrics and Gynaecology Unit of your local hospital if they have such an arrangement with an IVF clinic.

IVF using donated eggs, sperm or embryos

Donation may be an appropriate way forward if, for example, the male partner is unable to produce sperm capable of fertilising an egg, if a woman is unable to produce any eggs of her own or those produced are of a poor quality. Donation might also be used if one of the couple is at risk of passing on a serious inherited disease.

IVF treatment may also be offered using donated embryos if both partners are infertile but the woman is able to carry a baby to full term.

The availability of these treatments will depend on whether the clinic has access to supplies of donated eggs and sperm and has appropriate embryo storage and freezing facilities.

The decision whether to consider the use of donated eggs, sperm or embryos is naturally a very personal one and couples may wish to take up an opportunity of discussing the issues surrounding donation with a trained counsellor.

About the donors?

Sperm donors are men aged between 18 and 55 with a relatively high sperm count. All donors must undergo health screening to include hepatitis and sexually transmitted diseases such as HIV. Screening for HIV involves sperm being frozen and quarantined for at least six months, after which donors are retested. Donors can be paid up to £15 plus expenses per donation.

Egg donors are often women who have completed their families and are undergoing sterilisation, who are themselves having IVF treatment or who simply wish to help others. Similar selection and screening criteria apply as for sperm donors. Some clinics do not wish to take even a slight risk of HIV transfer from an egg and quarantine all embryos created from donated eggs for a period of six months. The donor is then retested. Occasionally a clinic will treat a patient with sperm or eggs from a donor who is already known to them.

When children reach the age of 18 they will be able to find out from the HFEA (after appropriate counselling) whether they were born as a result of egg, sperm or embryo donation. They will also be able to discover if they are related to someone they intend to marry. This information will also be given to 16 year-olds who want to marry before their 18th birthday.

ICSI (INTRA CYTOPLASMIC SPERM INJECTION)

ICSI is a relatively new technique whereby a single sperm is injected directly into an egg to aid the creation of an embryo. Up to three embryos created in this way may be transferred to the womb during any one treatment cycle in the same way as with conventional IVF.

ICSI may be appropriate where the male partner has very few sperm or where the sperm have poor or no motility. It is often necessary, for example, when the sperm sample is relatively small or sperm has to be extracted surgically. In some cases ICSI may be successful where conventional IVF fails to produce viable embryos because of a low fertilisation rate.

As the success of ICSI treatments is dependent to a very high degree on the skills and experience of its practitioners, the HFEA has introduced special competency assessment and licensing for them.

Chances of success

The success rate for ICSI has increased rapidly in the last few years, and in 1997-8, 8394 fresh embryo, stimulated cycles involving the patient's own eggs reached embryo transfer, resulting in 1850 births – a live birth rate of 22% per embryo transfer. However your chances of success will very much depend on your own individual circumstances (see pages 11-12).

Risks of ICSI

Concern has been expressed about the potential side effects of ICSI treatment, mainly because of the risk of injecting an abnormal sperm.

Whilst there are few serious doubts about the ICSI technique itself, it is possible that genetic disorders which led to the low sperm count or reduced motility in the father's sperm may be passed on to a son. So far there is mixed evidence about an increased risk of birth defects as a result of this treatment.

Whilst the ICSI procedure itself is unlikely to change, it remains a relatively new technique and further information concerning possible risk and safety issues is

regularly produced. If appropriate, a clinic licensed to perform ICSI will be able to provide a couple with up-to-date information and discuss the potential risks with prospective patients. The HFEA also recommends that men undergoing ICSI receive genetic counselling.

GAMETE INTRA FALLOPIAN TRANSFER (GIFT) using donated eggs or sperm

If tests establish that there is nothing wrong with the woman's fallopian tubes or the cause of a woman's infertility cannot be explained, a treatment known as GIFT may be offered. As with IVF, GIFT involves collecting eggs from a woman and mixing them with sperm. However, unlike IVF, the sperm and eggs mixture is immediately replaced into the woman's fallopian tubes so that fertilisation occurs inside the body.

The HFEA does not regulate GIFT if the woman's own eggs and her partner's sperm are used. However, if necessary, this treatment can be carried out using donated sperm or eggs, and these treatments are regulated and recorded by the HFEA.

As with IVF, no more than three eggs may be replaced during one treatment cycle, regardless of whether a woman's own or donated eggs are used. Such a limit reduces the risk of multiple birth (see page 12).

Because the number of these treatments where donor eggs or sperm are used is so small, clinics' live birth rates for those procedures are not reported in 'The Patients' Guide'. Some clinics offer combined treatment cycles in which both GIFT and IVF are carried out together. Live birth rates for these combined cycles are also not reported in the 'The Patients' Guide' as there are too few to provide reliable statistics.

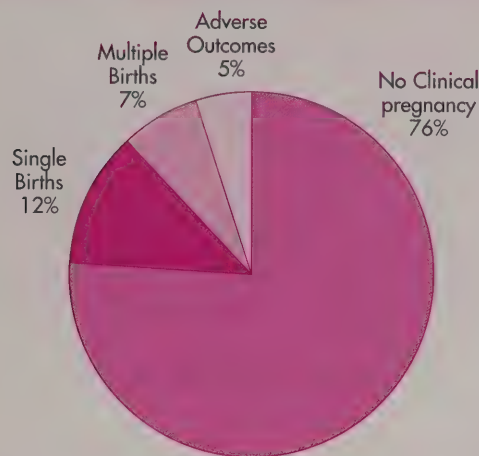
Treatments not licensed by the HFEA

There are a number of new clinical procedures which, while technically possible, have not been proven safe for both the intended child and the mother. Although such treatments may be available abroad, patients should be aware that they may not be of proven value and may be associated with a high risk to themselves or to a potential child.

Chances of Success

Only about one in six IVF treatment cycles is successful.

FIG. 2 results of ART cycles



Adverse outcomes include ectopic pregnancies, miscarriages, still births and neo natal deaths

There are many factors that influence a woman’s chances of having a live birth. Important factors include the following.

1. The age of the woman

The main factor that influences the outcome of the treatment is the age of the woman whose eggs are used in treatment (see FIG.3 below). In addition, the rates of miscarriage and chromosome abnormalities, such as Downs’ Syndrome, increase as women age. As the rate at which follicles disappear from the ovaries accelerates at the age of 37.5 years, two live birth rates per treatment cycle are given in the accompanying ‘Patients’ Guide to IVF Clinics’: one for all women and another for women below the age of 38. This also fairly represents clinics treating relatively large numbers of older women.

2. Previous pregnancies

Women who have been pregnant before, or who have had a previous IVF birth, have a higher chance of conceiving with IVF treatment.

3. The duration of infertility

This refers to the length of time a couple has been trying to have a family. FIG.4 shows that the live birth rate is lower the longer a couple has been infertile. This effect is most marked in long-standing infertility, whatever the age of the woman.

FIG. 4 livebirth rates by duration of infertility

Duration of infertility (years)	Number of cycles	Livebirth rate (%)		
		Per treatment cycle	Per egg collection	Per embryo transfer
0	2258	13.3	15.6	17.9
1-3	8407	15.3	17.2	19.5
4-6	13483	14.0	15.7	18.3
7-9	7017	12.9	14.4	17.0
10-12	3701	12.4	13.9	16.4
over 12	2092	8.6	9.7	11.8

All results are adjusted for woman’s age

FIG. 3 IVF live birth rate by womens age (using own eggs)



4. Previous IVF attempts

It has been shown that the live birth rate is highest at the first IVF attempt as the total number using IVF include those who are the most fertile. A woman's first cycle of IVF carries an average 17.4% success rate, but this dips to 14.4% by the fifth attempt. Couples are advised to discuss the outcome of each cycle with their medical advisors before embarking on repeated attempts.

Number of embryos replaced

It is advisable to discuss with the clinic how your individual circumstances might influence the decision on the number of embryos that should be replaced during your treatment cycle.

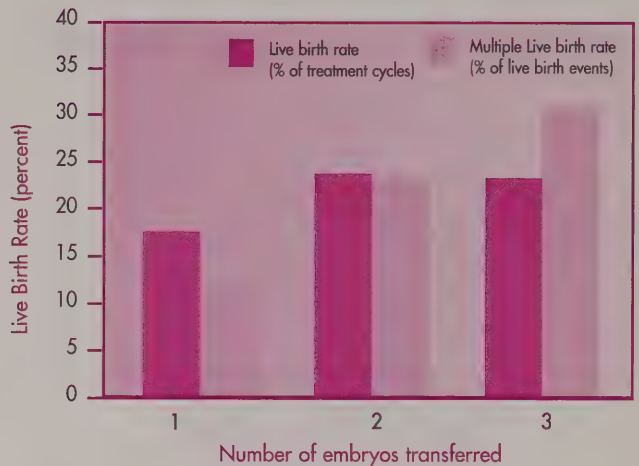
It is often thought that replacing the maximum of three embryos gives the greatest chance of achieving a pregnancy. However, FIG.5 shows that the live birth rate for treatments where two embryos are replaced (provided that more than four embryos were created) is almost identical to the live birth rate for treatments where three embryos are replaced. Replacing three embryos increases the chances of multiple births. There is no advantage, and there may be a considerable risk, in replacing three embryos.

It is essential to consider a clinic's policy for reducing the chances of multiple births. Some clinics have a policy of replacing only two embryos in each IVF cycle or of not using stimulation drugs in DI. These policies are designed to reduce the chance of multiple birth. The clinic should discuss these issues with you thoroughly in the light of your own circumstances.

The multiple live birth rate shown in FIG. 5 is calculated as the percentage of live birth events.

FIG. 5 live birth & multiple birth rates by number of embryos transferred

(more than 4 embryos available for transfer)



Risks of multiple birth

Although the prospect of twins or triplets may seem attractive, there are many serious risks associated with multiple births. Research has shown that multiple births can lead to a much higher risk of:

- complications during pregnancy;
- premature birth and low weight birth;
- disability;
- death of infants at, or within, 28 days of birth (known as neonatal death).

Low birth weight babies are much more likely to suffer from serious, life-long, health problems, such as cerebral palsy. Compared to the average birth weight of 3.3 kg for single babies, the average birth weights are 2.5 kg for twins and 1.8 kg for triplets.

The risk of stillbirth and neonatal death is also greater in a multiple birth than for single babies.

For single births from IVF treatment the rate of stillbirth and neonatal death is under 1%. The rate rises to 4.7% for twin births and 8.3% for triplet births.

In addition to the serious risks to the babies' health, a multiple birth can create enormous strains for the parents, including financial difficulties and emotional and physical exhaustion. In some cases the joys of parenthood are greatly reduced by these problems. You should give very careful consideration to limiting the number of embryos replaced to two in order to minimise the chance of triplets.

The cost of treatment

It is important to be clear from the start (whether or not you are receiving treatment in a NHS hospital) if there are charges and exactly what they cover.

Most clinics offer wholly fee paying treatment. Some IVF centres in NHS or university hospitals are also fee paying. If you have a private health scheme you should find out whether your scheme will fund any part of the investigations or treatment.

The cost of fertility treatment varies from clinic to clinic. DI treatment can cost between £100 and £500, and IVF about £800 to £3,000 per treatment cycle.

Each clinic should give you clear information about its current charges, although the way in which clinics do this varies. Some quote a standard amount for a complete treatment cycle. Each attempt at achieving a pregnancy is called a 'treatment cycle'. Other clinics list separately their charges for different tests, the drugs required, the various stages of treatment and counselling, follow-up consultations and embryo freezing and storage.

It is therefore important always to be clear about how much a full treatment cycle will cost including any additional charges for items such as drugs, consultations or embryo storage.

In addition, it is helpful to ask how much of the fee is refundable if it becomes necessary to abandon a treatment cycle.

Will I get NHS funding?

Some clinics operate under the NHS and offer treatment free of charge to patients sponsored by their local health authority. There is no clear way of showing which clinics operate in this way as some local health authorities contract out such services to otherwise private clinics. Similarly, some clinics located on NHS premises are funded separately and may make a charge for treatment. (In these circumstances the treatment is not NHS treatment.)

If you are seeking treatment on the NHS, you will need first to find out whether your local health authority is

willing to pay for treatment and, if so, on what conditions. Whether treatment is available to you through the NHS will depend upon a number of factors. Each health authority decides what funding they will allocate to the treatment of infertility and the types of treatment they will offer. If they do fund treatment, most health authorities have eligibility criteria for access to that funding. Contact your local health authority or your IVF unit for more information. NIAC, Child and Issue may also be able to help (see pages 19-20).

Counselling

Before proceeding with treatment clinics must offer you the opportunity to receive counselling.

Counselling provides an opportunity to discuss with an impartial person any concerns you may have about your treatment, its implications for you or infertility generally. However, you do not have to accept offers of counselling if you do not feel it would be helpful.

The HFEA Code of Practice sets out the types of counselling that should be available through licensed clinics. These include:

- *implications counselling*: to enable the people concerned to understand the implications of the proposed course of action for themselves, for their family and for any children born as a result. This may be particularly relevant for people considering treatment with donated sperm, eggs or embryos. This may also include genetic counselling.
- *support counselling*: to give emotional support at times of particular stress, e.g. when there is a failure to achieve pregnancy, and
- *therapeutic counselling*: which aims to help people cope with the consequences of infertility and treatment and resolve the problems that these may cause. It includes helping people to adjust their expectations and to accept the situation.

While all licensed UK clinics must offer counselling, the emphasis placed on it can vary between clinics. Some clinics insist on counselling before offering certain treatments. It may also be useful for you to contact one of the national support groups as they may be able to put you in touch with others who have experienced problems similar to your own (see page 19).

Embryo freezing and storage

Many embryos may be produced during IVF treatment. Clinics are only permitted to replace up to three embryos in a woman's womb during any one treatment cycle as replacing more than one embryo increases the likelihood of multiple pregnancy (see page 12).

Most clinics have storage facilities so that spare embryos can be frozen for use in a later treatment cycle if required. This may avoid the need for repeated drug stimulation, egg retrieval, sperm collection and fertilisation. However, not all embryos survive freezing and thawing, and the live birth rate per cycle from frozen embryos is usually lower than fresh embryo transfers. You should find out before you start IVF treatment whether the clinic offers embryo freezing.

Should any remaining embryos not be required for further treatment, they can be donated for the treatment of others, to research or allowed to perish. The individuals who gave their consent for their eggs or sperm to be used make the decision as to the use of these embryos. Their consents must agree before an embryo can be used or donated for treatment or research (see page 6).

Storage period for embryos and sperm

Patients storing embryos or sperm should be aware that they may not be stored indefinitely. Parliament set a limit of 10 years on the storage of gametes and a limit of 5 years on the storage of embryos. These periods may be exceeded in certain circumstances.

When the period of storage that is allowed comes to an end, any unused sperm or embryos must be removed from storage and allowed to perish. It is therefore important that you know the period of storage that applies to any embryos or sperm that you have in storage **and when this period expires**. This will help you to plan any future treatments with those embryos or sperm and give you time to consider whether or not you wish to donate them to another couple or for use in research. It is also important that you understand how the law in this regard affects sperm, eggs or embryos obtained from donors.

Your clinic will carry out regular reviews of the embryos and sperm that they have in storage and will try to remain in contact with you. It is of vital importance that you keep your clinic informed of any changes of address and respond promptly to any correspondence they send you. This will enable your clinic to ensure that you have plenty of time to deal with any issues arising from the storage of your embryos or sperm.

Choosing a clinic

See the 'Patients' Guide to IVF clinics' that accompanies this booklet, or call the HFEA for a copy.

It is advisable to contact two or more clinics and make a comparison of the services they offer in order to decide which best meets your needs. You should not look just at clinics' 'success rates' as these can vary and are affected by factors such as the age of the patients and the cause of their infertility. You should take into account the many other aspects that may well be relevant to you.

Amongst the factors that may influence your choice of clinic are:

- Costs
- Location of clinic/satellite arrangements
- Multiple birth rate
- Restrictions on treatment (including upper age limits or couples only)
- Waiting times
- Special expertise
- Availability, amount and cost of counselling
- Availability of embryo storage

It is useful to decide which factors are the most important to you, make a list of priorities and base your decision on these. Many people also find it helpful to prepare a list of questions to ask when they approach a clinic. It is important that you understand the cause of your infertility and why and how treatment will be given. You should always feel free to ask the clinic any questions that you consider important.

For example, some clinics with relatively high live birth rates may also have high multiple birth rates. Also,

many people like to know that they will feel comfortable in the clinic and with the clinic's staff. If possible you should visit one or more clinics and talk to the staff so as to get a feel for the way in which you will be treated. This will give you an opportunity to discuss the cost of treatment, assess the amount of time needed to travel to and from the clinic and find out how long you will have to wait for treatment to begin.

If your treatment is being funded by your health authority (NHS treatment), they may have a contract with a particular clinic and therefore you will not have a choice of which one you go to. If you are paying privately for treatment, it is important that you know you have a choice.

Summary of Questions to Ask clinics

You should ask for copies of the clinic's patient literature. This should provide you with details of the treatments they provide, costs, the outcome of treatment and potential complications. Do not hesitate to ask for further details if you do not understand the information provided. Other specific questions you may wish to ask when you attend the clinic are:

- Will there be any additional costs other than those quoted?
- What are the possible side effects of the drugs and procedures involved in treatment?
- Does the clinic normally use drugs in IVF/ICSI treatment?
- Can I see a woman doctor?
- What is the clinic's live birth rate per treatment cycle started, per egg collection, per embryo transfer?
- How does the clinic involve the male partner in the treatment?
- How many treatments are carried out each year?
- Are there any restrictions to treatment at the clinic?
- What tests would be carried out by the clinic?
- What opportunity will we be given to discuss fully with the doctor the causes of our infertility?
- Will we be seen by the same doctor throughout?
- Is there a waiting list for treatment?
- How many times will I have to visit the clinic?
- What counselling is available?
- Does the clinic have a patient support group?
- What are the chances of multiple birth at this clinic?
- What is the clinic's policy regarding the number of embryos replaced?
- What is the clinic's policy for cancelling treatment if too few or too many eggs develop?
- Does the clinic offer genetic screening for cystic fibrosis or other genetically transmitted diseases and conditions?
- What is the clinic's policy for decreasing the risk of OHSS?
- What will happen if we achieve a pregnancy?
- What will happen if we don't achieve a pregnancy?
- How many cycles of treatment does a clinic recommend before considering other treatment options?
- Are any of the clinic's facilities shared with other units, such as the maternity unit?
- Does the clinic have access to donor sperm/eggs/embryos?
- How long has the clinic been established?
- What is the policy on screening donors?
- Does the clinic have embryo storage facilities?
- Is combined IVF & GIFT treatment offered? If so, what is the clinic's live birth rate per treatment cycle started? Per egg collection? Per embryo transfer? What is the clinic's multiple birth rate for this treatment?
- What other treatments does the clinic offer?
- Does the clinic have transport or satellite treatment arrangements with a hospital closer to my home?

1. Should I treat the list of clinics as a 'league table' and go to one with the highest live birth rate?

No. Many other factors can be equally as important. These can include the location of the clinic, costs, waiting times, its experience of special techniques and its policy on multiple births. Patients must feel comfortable and confident with their choice, and they should use our Guide as a starting point rather than as a source of comprehensive information.

2. Will I get NHS funding?

In the UK about 25% of IVF treatments are provided by the NHS. You will first need to find out whether your local health authority is willing to pay for treatment and, if so, under what conditions. Whether treatment is available to you on the NHS will depend upon a number of factors. Each health authority decides what funding they will allocate to the treatment of infertility and the types of treatment they will offer. If they do fund treatment, most health authorities have eligibility criteria for access to that funding.

3. Why is the clinic required to make an assessment of my suitability? What is 'welfare of the child'?

The Human Fertilisation and Embryology Act 1990 states that, before offering anyone treatment, a clinic must: *'take account of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth'.*

This means that the clinic will ask you a number of personal questions. Your ages and the medical histories of you and your families will be considered. So too will the needs of any child or children who may be born, and your ability to meet those needs.

Clinics should also consider any risk of harm from neglect or abuse to any child who may be born. They will also take account of the effect of a new baby upon any existing child of the family. Clinics must seek to satisfy themselves that the GP of each prospective parent knows of no reason why either of them should not be offered treatment. Before seeking such

reassurance from your GP, the clinic must obtain the patients consent. Failure to give consent will be taken into account by the clinic in considering whether or not to offer treatment.

Some clinics, as a matter of policy, do not offer treatment to single women or to unmarried couples. Most clinics set upper age limits for women they are prepared to treat, although the HFEA has not itself set an age limit.

In considering you for treatment, clinics will take all these factors into account as well as the possible effects of the treatment on your own welfare.

4. What is the clinic obliged to give to me/tell me?

All UK licensed clinics must supply written information to prospective patients before offering treatment. This information should give details about the services it offers, any risks involved, its costs, previous live birth rates and its complaints procedure. This literature should be comprehensive and easy to understand, although staff at the clinic will explain any points that are unclear. The HFEA's Code of Practice gives details of the kind of information which clinics must provide.

5. What consents will I be asked to give?

Before beginning treatment the clinic must obtain your written 'informed' consent. This means that you have been given information about the procedures, had the opportunity to discuss the treatment with the clinic's staff, had the opportunity to receive counselling and had time to think about your decision. You may choose to change or withdraw your consent at any time.

You will also be offered counselling before proceeding with the treatment. This provides an opportunity to discuss with an impartial person any concerns you may have about your treatment, its implications for you or infertility generally. Some people find counselling particularly helpful when they are considering whether to receive treatment with donated sperm or eggs. However, you do not have to accept offers of counselling if you do not feel it would be helpful for you.

6. *What decisions will I be asked to make?*

When you decide to begin treatment you will be expected to make further choices such as: the number of embryos to be replaced to the womb; whether you wish spare embryos to be frozen for further use; or whether you wish them to be donated or used in research. At every stage you will be guided by your clinic.

7. *Will my treatment remain confidential?*

Yes. In addition to a doctor's responsibility to keep your medical records confidential, the Human Fertilisation and Embryology Act 1990 imposes particular duties in respect of IVF patients and donors. The clinic may not disclose information about your treatment to anybody else (apart from clinic staff), even your GP, without first obtaining your written consent. To do so, other than in very exceptional circumstances, is a criminal offence.

8. *If donor eggs or sperm are used, will my treatment still remain confidential?*

Where donated sperm or eggs have been used the identity of the donor is kept strictly confidential so you cannot learn his or her identity, but you may obtain some non-identifying information about the donor. Similarly, your name will not be known to the donor. However, clinics are required to collect and pass on information about the donor, recipient and treatment cycle to the HFEA for its confidential Register. The purpose of the Register is to enable people over the age of 18 (or 16 if contemplating marriage) to find out whether they were born as a result of licensed fertility treatment (i.e. donor insemination, *in vitro* fertilisation) and, if so, whether they are related to someone they intend to marry. There may be provisions in the future for children born of such treatments to obtain further information about donors.

9. *How can I complain?*

The HFEA requires every licensed clinic to have its own complaints procedure, and the handling of complaints is monitored as part of the HFEA's inspection procedure. If a patient, donor or anyone else feels that

a clinic has not dealt with their complaint adequately, then they should write to the HFEA.

10. *What will happen if the treatment is successful?*

The extent to which clinics remain involved after treatment varies. Some clinics may carry out a pregnancy test and some provide ante-natal care. Others discharge patients to the care of their own GP or consultant. These differences may be important to you. You should consider discussing them with the clinic.

The clinic needs to know the outcome of your treatment and will be able to offer advice and support.

11. *What will happen if the treatment is not successful?*

If the treatment does not lead to a pregnancy then there may be several options. In any event, the clinic should offer you advice and counselling. You may decide to try again, try a different type of treatment or withdraw from further treatment.

You might ask the clinic how many cycles of treatment are given before further investigations are undertaken or other forms of treatment considered.

The staff at the clinic, the independent counsellor and your GP or consultant (if they have been informed of the treatment) should be able to offer advice and support.

Information and advice about fertility treatment is available from your GP or consultant and from the doctor, nurses and counsellor at the licensed clinic. Each clinic produces its own patient information, describing the services available and explaining what is involved in treatment.

In addition, information is available from the following organisations.

Patient Organisations

CHILD

(The National Infertility Support Network)

Provides factsheets, a quarterly magazine, publications, medical advice and emotional support including helplines, local groups and local and national meetings. They can be contacted at:

Charter House, 43 St Leonards Road
Bexhill-on-Sea, East Sussex TN40 1JA

Tel: 01424 732361

Fax: 01424 731858

E-mail: office@email2.child.org.uk

<http://www.child.org.uk>

ISSUE (The National Fertility Association)

Members receive independent individual support and information. Members and non-members alike can telephone for help. Callers are answered personally 24 hours a day. Confidential telephone counselling by qualified counsellors is available to all every weekday evening. They can be contacted at:

114 Lichfield Street, Walsall WS1 1SZ

Tel: 01922 722888

Fax: 01922 640070

E-mail: webmaster@issue.co.uk

<http://www.issue.co.uk>

DAISY NETWORK

Premature Menopause Support Group

Support group for girls and women who suffer early ovarian failure. Exchange information on IVF, HRT and on ways to have a family through egg donation, surrogacy or adoption. Provides informal telephone counselling by members and quarterly newsletter.

They can be contacted at:

P.O. Box 392, High Wycombe, Bucks, HP15 7SH

You can call Monique Francis on 01628 473446

(evenings) or 0181 569 1234 ext 2648 Mon, Wed, or Friday (office hours)

DI NETWORK

Provides contact and support for those who have children, or plan family creation, conceived using donated gametes through donor insemination (DI) and IVF with donor sperm or donated eggs.

They can be contacted at:

P O Box 265, Sheffield S3 7YX

Tel/Fax: 0181 245 4369

<http://www.issue.co.uk/dinetwork>

MISCARRIAGE ASSOCIATION

Provides support and information on the subject of pregnancy loss.

They can be contacted at:

c/o Clayton Hospital, Northgate, Wakefield,
W. Yorks WF1 3JS

Tel: 01924 200799

Fax: 01924 298834

NATIONAL CHILDBIRTH TRUST (NCT)

Offers information and support in pregnancy, childbirth and early parenthood. They aim to give every parent the chance to make informed choices.

They can be contacted at:

Alexandra House, Oldham Terrace, London W3 6NH

Tel: 020 8992 8637

9.30-4.30 Monday to Friday

Fax: 020 8992 5929

NATIONAL ENDOMETRIOSIS SOCIETY

Provides a helpline, local groups and clubs, a newsletter and other publications, workshops and conferences.

They can be contacted at:

50 Westminster Palace Gardens,
Artillery Row, London SW1P 1RL
Tel: 020 7222 2776
Fax: 020 7222 2786

NATIONAL INFERTILITY AWARENESS CAMPAIGN (NIAC)

A lobbying organisation campaigning for NHS funding for all infertility treatment on an equal basis across the UK. Gives advice on the current situation with regard to NHS funding and on campaigning/lobbying activities.

They can be contacted at:

PO Box 2106, London W1A 3DZ
Tel: Freephone 0800 716345

TWINS & MULTIPLE BIRTHS ASSOCIATION (TAMBA)

Provides support for families with twins, triplets or more, and for professionals involved with their care. Network of local Twins Clubs, specialist support groups, publications and an information pack.

They can be contacted at:

PO Box 30, Little Sutton, South Wirral L66 1TH
Confidential helpline: 01732 868000 open:
7pm-11pm weekdays, 10am-11pm weekends.

Information line: 01342 843880

MULTIPLE BIRTHS FOUNDATION

Provides professional support and information about all aspects of multiple births.

They can be contacted at:

Queen Charlotte's & Chelsea Hospital,
Goldhawk Road, London W6 0XG
Tel: 020 8383 3519
Fax: 020 8383 3041

PROGRESS EDUCATIONAL TRUST

Provides information on fertility and genetics, and promotes discussion on their ethical and legal implications. Publishes a news journal, 'Progress in Reproduction'.

They can be contacted at:

140 Gray's Inn Road,
London WC1X 8AX
Tel: 020 7278 7870
Fax: 020 7278 7862
E-mail: admin@progress.org.uk
<http://www.progress.org.uk>

Other Organisations

BRITISH INFERTILITY COUNSELLING ASSOCIATION (BICA)

BICA aims to promote high quality, accessible counselling services for people with fertility problems. The Association offers information to patients who are seeking details of counsellors specialising in infertility.

They can be contacted at:

69 Division Street, Sheffield S1 4GE

'The Patients' Guide to IVF Clinics'

'The Patients' Guide to DI'

'Egg Donation'

(published by the HFEA)

'Fertility Problems: a simple guide' by Ruth Chambers

(Radcliffe Medical Press, 1999)

'In pursuit of parenthood: real life experiences of IVF'

by Kate Brian; Bloomsbury (1998)

'Infertility in practice' by Adam Balen and Howard

Jacobs; Churchill Livingstone (1997) (VERY SPECIALIST)

'The Infertility Companion: a users guide to tests,

technology and therapies' by Anna Furse; Thorsons

(1997)

Families following assisted conception - what do we tell

our child', by Alexina McWhinnie; University of

Dundee (1996)

'Infertility: your questions answered' by S.L. Tan and

H.S. Jacobs; McGraw-Hill Book Company (1996)

'Infertility - a sympathetic approach' by Professor Lord

Robert Winston; Vermilion (1996)

'Male infertility - men talking' by Mary-Claire Mason;

Routledge (1993)

'The gift of a child' by Robert and Elizabeth Snowden;

University of Exeter Press (1993)

Please note this list is not exhaustive.

Abandoned cycle

In IVF where a treatment cycle is cancelled after commencing administration of drugs, but at any stage before embryo transfer.

Assisted hatching

The mechanical, chemical or laser breaching of the gelatinous coating of the egg.

Cervical mucus

The secretions surrounding the cervical canal. The amount and texture changes during ovulation to allow sperm penetration.

Counselling

All licensed clinics are required to offer patients counselling. Such counselling aims to enable the patient to understand the implications of treatment, to give emotional support and to help the patient cope with the consequences of treatment.

Cryopreservation

The storage of gametes or embryos by freezing at low temperatures.

Donor Insemination (DI)

The insemination of donor sperm into the vagina, the cervix or the womb itself.

Egg collection

Procedure by which eggs are collected from the woman's ovaries by using an ultrasound guided needle or by using a laparoscope (an instrument for looking into the abdomen) and a needle. Also known as egg retrieval.

Embryo

A fertilised egg up to eight weeks of development.

Embryo freezing

Embryos not required for treatment in a cycle can be frozen and stored for future use. Freezing is also known as cryopreservation.

Embryo transfer

Transfer of one or more embryos to the uterus.

Embryo storage

The storage of one or more frozen embryos for future use.

Endometriosis

A female condition in which endometrial cells, which normally line the uterus, implant around the outside of the

uterus and/or ovaries, causing internal bleeding, pain and reduced fertility.

Epididymis

Coiled tubing outside the testicles which store sperm.

Fallopian tube(s)

The tubes between the ovaries and the uterus. After release of the egg from one of the ovaries, the tube transports the egg to the uterus.

Fetus

The term used for an embryo after the eighth week of development until birth.

Follicle(s)

A small sac in the ovary in which the egg develops.

Gamete

The male sperm or the female egg.

Gamete Intra Fallopian Transfer (GIFT)

A procedure in which eggs are retrieved from the woman, mixed with sperm and immediately replaced in one or other of the woman's fallopian tubes so that they fertilise inside the body.

Gonadotrophins

Drugs used to stimulate the ovaries similar in composition to natural follicle stimulating hormone (FSH) produced by the pituitary gland

Hamster test (HEPT)

A test of the fertilising ability of human sperm by observing their penetration into the hamster egg.

HFEA

Human Fertilisation and Embryology Authority.

Intra Cytoplasmic Sperm Injection (ICSI)

A variation of IVF treatment where a single sperm is injected into the inner cellular structure of the egg.

Intrauterine Insemination

Insemination of sperm into the uterus of a woman.

In Vitro Fertilisation (IVF)

Eggs and sperm are collected and put together to achieve fertilisation (IVF) outside the body.

Live birth

The delivery of one or more babies.

Live birth rate

The number of live births achieved from every 100 treatment cycles commenced.

Menstrual cycle

A cycle of approximately one month in the female during which the egg is released from an ovary, the uterus is prepared to receive the fertilised egg and blood and tissue are lost via the vagina if a pregnancy does not occur.

Microsurgical Epididymal Sperm Aspiration (MESA)

Retrieving sperm directly from the epididymis.

Multiple birth

Birth of more than one baby from a pregnancy.

Multiple birth rate

This is the percentage of all births in which more than one baby was born.

Multiple pregnancy

This is the percentage of all pregnancies in which two or more fetal hearts are present.

Neonatal death

The death of a baby within 28 complete days of delivery.

Ovarian Hyperstimulation Syndrome (OHSS)

A serious complication following stimulation of the ovaries with gonadotrophin drugs.

Ovary

One of a pair of female reproductive organs which produce eggs and hormones.

Partial Zona Dissection (PZD)

A variation of IVF treatment in which a small hole is made in the outer membrane of the egg using a small glass needle, thereby easing the passage of sperm into the egg under their own motion.

Percutaneous Epididymal Sperm Aspiration (PESA)

Retrieving sperm directly from the coiled tubing outside the testicles that store sperm (epididymis) using a needle.

Preimplantation Genetic Diagnosis (PGD)

Techniques by which embryos fertilised *in vitro* are tested for specific genetic disorders (e.g. cystic fibrosis) or other characteristics such as sex before transfer to the uterus.

Pregnancy rate

The number of pregnancies achieved from every 100 treatment cycles commenced.

Spermatid

An immature sperm cell.

Stillbirth

The birth of a dead infant.

Stimulation drugs

Drugs used to stimulate a woman's ovaries to produce more eggs than usual in a monthly cycle; also known as superovulatory drugs.

Stimulated cycle

A treatment cycle in which stimulation drugs are used to produce more eggs than usual in the woman's monthly cycle.

Superovulation/stimulation

The stimulation of a woman's ovaries with drugs to produce more eggs than usual in a monthly cycle.

Testicular Sperm Extraction (TESE)

Retrieving sperm directly from the testis.

Testis

Testicle or male gonad.

Treatment cycle

- IVF with fresh embryos: a cycle begins with the administration of drugs for the purpose of superovulation or, if no drugs are used, with the attempt to collect eggs;
- IVF with frozen-thawed embryos: a cycle begins with the removal of the stored embryo in order to be thawed and then transferred;
- DI: a cycle begins when the first insemination with donor sperm takes place.

Unknown outcome

The outcome of a clinical pregnancy is unknown due to incomplete information being returned by a clinic to the HFEA.

Unstimulated cycle

No drugs were given to stimulate egg production.

Zona drilling (ZD)

Acid released to dissolve the gelatinous coating of the egg leaving a hole through which the sperm can enter.

The HFEA — who we are and what we do

The Human Fertilisation and Embryology Authority (HFEA) was set up in 1991 to licence and regulate clinics which provide:

- *in vitro* fertilisation (IVF) treatment
- donor insemination (DI) treatment
- gamete intra fallopian transfer (GIFT) where donated sperm or eggs are used in treatment
- storage of gametes or embryos.

The HFEA also licenses clinics that carry out research involving human embryos. These activities can only be carried out if the clinic obtains a licence from the HFEA. As well as licensing research and treatment clinics, the HFEA also:

- publishes a Code of Practice giving guidance to clinics on how they should carry out licensed activities;
- keeps a confidential register of information about donors, patients and treatments;
- gives advice and information to licensed clinics;
- gives information and advice to people seeking fertility treatment, to donors and the general public.

The HFEA exists to safeguard, protect and reassure patients, professionals and the public about licensed infertility treatments and human embryo research.

The HFEA inspects all licensed treatment centres annually, requiring and helping all centres to achieve, and adhere to, the high standards in our Code of Practice. The HFEA remains one of the few national statutory bodies of its kind in the world.



The Human Fertilisation and Embryology Authority
Paxton House, 30 Artillery Lane, London E1 7LS
Tel: 020 7377 5077 Fax: 020 7377 1871
website at <http://www.hfea.gov.uk>